High Needs Collaborative

The Lost Generation?

A discussion paper concerning people with a serious mental illness as they enter old age

1 Purpose of this paper

1.1 Hafal and colleague organisations in the High Needs Collaborative (see below) are committed in 2016 to taking up the cause of *older service users* as part of their three year programme of work to highlight and improve the lives of specific groups of people affected by serious mental illness.

1.2 This paper is intended to define who we are talking about and to start to scope what the key issues are and how we might make a difference.

2 The High Needs Collaborative

2.1 The High Needs Collaborative is a longstanding alliance of voluntary organisations which aim to support the recovery of people with a serious mental illness in Wales. By "serious mental illness" we mean people with schizophrenia, bipolar disorder, or other illnesses which require substantial support – about one in thirty of us will experience such illness. Traditionally this client group has been supported by secondary mental health services in Wales but increasingly many are supported at primary care level only.

2.2 The Collaborative's activities are led by people with a serious mental illness and their carers through the governance of the four organisations and by direct engagement as activists and volunteers in specific campaigns.

2.3 The Collaborative's membership varies and in this instance our work with older people is supported by Hafal, Bipolar UK, Diverse Cymru, and Crossroads Mid and West Wales.

3 Who are we talking about?

3.1 The client group we want to prioritise are *older people* with a serious mental illness as defined by the Collaborative's usual criteria.

3.2 By "older people" we mean those in late middle age, perhaps typically 55 and upwards, who are becoming affected by changes which occur in later life including changes in their own physical and mental health and in their wider life – matters such as bereavement, retirement, etc.

3.3 By “serious mental illness” we mean (as in 2 above) the sort of illnesses which approximately one in thirty of us will experience at some stage in our lives including schizophrenia, bipolar disorder, and other illnesses which require substantial support. For clarity we refer here to illnesses which are traditionally associated with onset in youth or young adulthood, though we are aware of (and cover below) the phenomenon of late-onset of these types of illness.

3.4 Our primary focus is not on those with *dementia* (including Alzheimers Disease, vascular dementia, etc) but we recognise that dementia is one of the significant health risks for our defined client group (as for all of us) – and so dementia is considered below as *an issue for our defined client group*. We also recognise that *depression* and *substance misuse* can be health risks of old age: again our specific concern would be how these problems affect our particular client group of people who have experience of serious mental illness as defined above.

3.5 We recognise that there is currently substantial public interest in dementia and we welcome this as one of the ways in which mental health is becoming more openly considered by the public. But we also believe it is important to draw attention to those who have other forms of mental illness as they enter older age.

4 Why are we concerned?

4.1 Our concern is partly based on external information and research about this client group in the UK and beyond (more on this below). But actually it will be seen that information and research in this field is scant and inconclusive.

4.2 Our concern *mainly* comes from our own members and clients whom, as longstanding organisations, we have got to know as they have aged. We have observed that these clients have tended to drift away from our view and away from mental health services generally – and often *not* in a “planned” way based on reducing need.

4.3 We know that this is partly owing to requirements of some services that clients should be “of working age” (though this has begun to change not least owing to revised Welsh Government policy and discrimination law).

4.4 We also believe that the proper expectation that services should move people on towards recovery has discouraged some services from engaging with older clients on the grounds that they may be perceived to be less likely to “move on” - because they are from an earlier generation of more “institutionalised” clients, or just because they are older. Some older clients may of course share these lower expectations of themselves.

4.5 Older clients may be neglected because they give less overt cause for concern. There is evidence that positive symptoms of psychosis reduce in old age – and that may of course be a good reason to reduce or withdraw some forms of treatment and care – but this does not mean that the wider needs of these clients are not substantial and possibly greater.

4.6 We are also concerned that many clients as they get older lose their main or only carers (particularly their parents) and without those carers' advocacy and encouragement older clients may be neglected.

4.7 Although the rigid age distinctions in mental health services are beginning to break down, it seems evident that services designed to treat the illnesses of old age, including dementia, are not readily suited to assisting our client group.

4.8 Finally, it is well known that people with a mental illness live much less long than the average. This means there are sadly less of them in old age and their needs may consequently be that much less noticed.

4.9 For all these reasons this client group is arguably a "forgotten generation".

5 What external information and research is available on this client group?

5.1 There is remarkably little information and research on the *specific* issue of serious mental illness (as defined here) in later life (still less on those clients in this category with protected characteristics – though there is useful research in relation to *dementia* such as Black and minority ethnic people with dementia and their access to support and services) – and this lack of information and research is widely acknowledged as shown in 5.5 and 5.6 below.

5.2 The World Health Organisation's key statement on Mental Health and Older Adults confines its recommendations effectively to dementia and depression.

5.3 In its report All Things Being Equal (2009) the Mental Health Foundation explores the evidence for differences between services as defined by age, for example:

> *Service users have spoken of being unable to access their drop-in and day centres once they turned 65, resulting in feelings of loneliness and isolation, a lack of interaction with peers and reduced staff support (Age Concern, 2007).*
>
> *Protocols to manage this transition from adult to older age services are not consistently used and practice varies across services (Mind, 2005).*
>
> *Older people who experience mental health problems for the first time may also be disadvantaged by current service structures.*

5.4 There is some limited research on schizophrenia in later life. In Treating Older Adults With Schizophrenia: Challenges and Opportunities (2013) Jeste and Maglione state:

> *Positive symptoms of schizophrenia tend to become less severe, substance abuse becomes less common, and mental health functioning often improves. Hospitalizations are more likely to be due to physical problems rather than psychotic relapses. Physical comorbidity is a rule, however, and older age is a risk factor for most side effects of antipsychotics, including metabolic syndrome and movement disorders.*

Sustained remission of schizophrenia after decades of illness is not rare, especially in persons who receive appropriate treatment and psychosocial support—there can be light at the end of a long tunnel.

There are several critical gaps in the current knowledge regarding schizophrenia in late life *that represent research opportunities.*

5.5 On the specific issue of late onset schizophrenia King's College and the Maudsley NHS Trust state in their on-line advice:

Older people who are diagnosed with schizophrenia are offered the same treatment as younger people diagnosed with the illness – antipsychotic medication and talking therapies. Antipsychotics will be prescribed at lower doses for older people, though ***there has been very little research about very late onset schizophrenia-like psychosis to enable health professionals to know the best treatment approach.***

5.6 And in Bipolar disorder in older adults: a critical review (2004) Depp and Jeste state:

Common methodological problems in the published studies included small sample sizes, retrospective chart review, lack of standardized measures, overemphasis on inpatients, and dearth of longitudinal data. Strong evidence indicates that bipolar disorder becomes less common with age, accounts for 8-10% of late life psychiatric admissions, is associated with neurologic factors in late-onset groups, and is a heterogeneous life-long illness. Weak or inconsistent evidence was found for a higher prevalence of mixed episodes in older adults, a lower treatment response, and the association with lower family history in late-onset groups. ***Minimal information is available on bipolar depression in late life.***

Bipolar disorder in old age is a growing public health problem. Greater research on bipolar disorder in older people will assist in enhancing services to this group as well as inform research on bipolar disorder across the life span.

5.7 In The care needs of older people with bipolar disorder (2015) Dautzenberg *et al* studied older patients with bipolar disorder, concluding:

Less social participation was associated with a higher total number of needs and more unmet needs. Older bipolar patients report fewer needs and unmet needs compared to older patients with depression, schizophrenia, and dementia. A plausible explanation is that older bipolar patients had higher Global Assessment of Functioning scores, were better socially integrated, and had fewer actual mood symptoms, all of which correlated with the number of needs in this study. The results emphasize the necessity to assess the needs of bipolar patients with special attention to social functioning, as it is suggested that staff fail to recognize or anticipate these needs.

5.8 In summary there is little attention on the needs of this client group and scant research on which to base well-targeted medical treatment, let alone wider care and support.

6 What is the policy and legal context in Wales?

6.1 The Welsh Government's policy in relation to this client group is covered by Together for mental health - a strategy for mental health and wellbeing in Wales.

6.2 This strategy explicitly marks an end to age-specific policy on mental health. Specifically it requires that support is provide according to individual need rather than based on age.

6.3 So, in the context of this paper, a person who has (or develops) schizophrenia in old age might expect to receive equivalent services to those which an adult of working age might receive, duly adapted to their individual circumstances and needs (and similarly a person who develops dementia at a younger age might receive services equivalent to those received by an older person, again subject to their individual needs). In both instances the individual circumstances may in practice be very different and require different sorts of support – but the policy requirement nevertheless underpins the approach which should be taken.

6.4 Members of the High Needs Collaborative support this Strategy and indeed it is arguably *the benchmark for our campaigning work for older people with a serious mental illness*. Our concern is to see that the Strategy is actually implemented: this means that practice should not discriminate on grounds of age but *at the same time it should absolutely adapt to the particular needs which arise with age.*

6.5 It should be noted that the Strategy makes limited reference to the needs of older people with a mental illness as defined in this paper but an underlying principle of the Strategy is to develop an individualised, non-age-specific, non-discriminatory approach. It is important to test the Strategy's effectiveness in improving the lives of this specific group by reference to this principle.

6.6 Old habits die hard: services for adults of working age and for older people have long been divided and there are also longstanding professional distinctions in play. The challenge is not just to unite these services effectively but also to ensure that good practice is not lost in the process.

6.7 We are concerned that much attention is rightly given to the implication of an "all ages" approach for dementia services, while there has not been a focus on the client group considered in this paper. In theory they should clearly be assisted by the new Strategy but this will not necessarily be fulfilled just because the Strategy is in place.

6.8 The client group is also covered by the Welsh Government's Strategy for Older People in Wales: the Strategy does not explicitly refer to this specific client group and references to mental health are mainly to conditions arising from ageing. Ageing Well in Wales, the key agenda of the Older People's Commissioner for Wales, is also relevant, perhaps particularly in its emphasis on combatting loneliness and isolation.

6.9 Legislation in Wales should also assist this client group. In particular the Mental Health (Wales) Measure (2010) requires an all-ages Care and Treatment Plan for people using secondary mental health services: this should provide a firm platform to cover transition for individuals into old age and could also provide a means of ensuring fairness and consistency between people of different ages.

6.10 Meeting the social care needs of this client group will depend substantially on how the new Social Services and Wellbeing (Wales) Act 2014 is implemented.

6.11 Finally, the developing use of Human Rights legislation in relation both to health and ageing potentially provides an important lever for improving support to this client group.

7 How are different areas of these clients' lives affected?

7.1 In Wales all clients in receipt of secondary mental health services are entitled to a Care and Treatment Plan with sections covering nine "life areas": it seems appropriate therefore to look at each of these life areas and consider specific issues which may arise for service users as they reach older age (but note that these considerations can also apply to clients who are not in receipt of secondary mental health services):-

(i) Accommodation

Many older clients will have a settled home but some circumstances may result in difficult changes requiring significant support. These could include:

- A client living with carers may not be able to continue to live in the family home after a carer dies or moves into supported housing
- A client's own physical health may require a move to more suitable or supported accommodation

(ii) Education and training

Older clients should be able to take advantage of the opportunities available to all older people for education and training. Problems may arise if, for example:

- A client may cease to attend a supportive, mental health specialist education/training service as it is "not suitable" for older clients
- A client may require extra support to attend adult education or other general education/training opportunities available to all older people

(iii) Finance and money

In addition to challenges familiar to service users of all ages older clients may face specific problems, for example:

- A client may have difficulty with transition from working age benefits to state pension and older age benefits
- A client who has been in employment may have problems with a lower income on retirement or not working owing to sickness

(iv) Medical and other forms of treatment, including psychological interventions

As noted above there is poor research into the particular issues associated with medication for older clients. So, for example:

- A client may experience increased and possibly dangerous side effects from anti-psychotic medications which they have taken from a younger age
- A client may have difficulty getting the right adjustments to medication in response to reduced symptoms and/or increased risk from side-effects
- A client may experience increased deterioration in general physical health from long-term side-effects of medication
- A client may have difficulty negotiating a more complex mix of medication, perhaps to address depression in older age

Older clients may also have difficulty finding suitable psychological therapies, for example:

- A client being treated alongside patients with dementia may find no suitable psychological treatments are available
- A client may have difficulty accessing psychological therapies for specific problems which occur in old age such as bereavement and loneliness

This is probably the right place to mention the issue of clients who develop dementia in addition to their existing mental illness:

- A client who develops dementia will need well-planned medical and social care which is sensitive to their complex needs

(v) Parenting or caring responsibilities

Older clients with parenting and caring responsibilities may encounter problems including:

- A client may take on caring responsibilities for a very elderly parent (who may have themselves been a carer for the client)
- A client may struggle to maintain contact with their own children and grand-children owing to physical health problems

(vi) Personal care and physical well-being

Older clients are likely to find the challenges of looking after themselves and their physical health harder, specifically:

- A client who owing to their illness has always had problems with daily routines of looking after themselves may be doubly challenged if their physical health deteriorates
- A client may experience increased problems with side-effects of medication (see iv above)
- A client may have difficulty accessing physical health-care owing to their mental illness
- Clients who have depended on older carers to assist with looking after themselves may lose this support

(vii) Social, cultural and spiritual

Loneliness and isolation are familiar challenges both for people with a mental illness and for many elderly people. People with as serious mental illness can therefore face compounded problems as they become older:

- A client who moves on from a "working age" day service may lose a key source of social contact
- A client who has been dependent on older carers may, on their death, lose not only care support but also a key means of maintaining social contact
- A client may be isolated on the death of their partner, siblings or friends
- A client may lose social contact if they have to move away from their long-term home environment into supported accommodation owing to physical health challenges

(viii) Work and occupation

As they get older many people with a mental illness will face challenges which are familiar to others in relation to employment - along with some specific issues:

- A client who has been in paid employment may face financial difficulty when their employment ceases or reduces
- A client may lose social contact through loss of employment, including occupation at "working age" specialist services (see vii above)
- A client may face problems trying to maintain employment into older age in spite of discrimination legislation

8 What about specific client groups?

8.1 If older people with a mental illness are in any case a marginalised group for whom services are often not specifically designed then clients from specific groups may face additional challenges.

8.2 Clients from black and minority ethnic groups may have difficulty getting support which is sensitive to their cultural needs; they may also have difficulty getting support which works effectively with their community's traditional or distinctive support systems for people with a mental illness and for elderly people.

8.3 There are also challenges in ensuring that support is appropriate and sensitive to older clients' gender, sexual orientation, religion, etc.

9 What about late onset mental illness?

9.1 This paper has mainly focused on clients who have had a mental illness from (typically) youth or early adulthood but we are also concerned about the significant number of elderly people who develop serious mental illness in later life: see for example the King's College and Maudsley NHS Trust advice on late onset schizophrenia in 5 above.

9.2 Many of the same considerations set out above will apply to this group but to these should be added the particular difficulties of older clients who have never been supported by what used to be seen as "working age" mental health services and may be treated therefore as having an illness of old age – not necessarily the right perspective.

9.3 Some late onset mental illnesses may indeed be related to old age but the principle of providing "all-ages" support services should mean that they can access the same or adapted services as those who develop similar illnesses earlier in life.

9.4 A specific example would be late onset psychotic symptoms (whether or not associated with old age) where clients should expect to be offered the range of treatments (medical and psychological) and support, adapted and supplemented according to individual need, as younger clients.

10 What about carers?

10.1 Everybody who works in mental health is familiar with the concern of carers growing older and wondering who will look out for the person they care for in the future. This is most familiar with parents of clients but can also of course apply to others including partners and siblings.

10.2 The age at which a client is left without the support of a long-term parent carer obviously varies widely but in our experience it is typically when the client is in their fifties

or sixties, when they are themselves in “transition” to old age and possibly encountering some of the problems set out in 6 above.

10.3 Spouses, partners, and sibling carers typically face different challenges: their capacity for caring may become limited as they themselves become older; and their own changing needs may involve major change, for example if they need to move into supported accommodation.

10.4 Some carers do have comfort in seeing the positive symptoms of illness ease for the person they care for – and if all goes well they can observe that person in settled and safe circumstances. But equally there may be disruptions and transitions for the cared-for person which can cause great anguish especially for elderly, often parent carers.

11 Next steps

11.1 This discussion paper is a starting point for the High Needs Collaborative to define more clearly the client group concerned and to consider further their specific needs.

11.2 The next step is to work with our clients and their carers to identify what practical steps can be taken to improve the lives of older people with a serious mental illness in Wales. To this end we propose to hold a consultation and dialogue with our members and stakeholders and, through social media, other clients and carers.

11.3 We aim to report the conclusions of this consultation and dialogue, together with our recommendations, in December 2016.

12 Contact

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